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A N A L Y S I S

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***From Hawaii to Maryland:
A Compilation of Qualitative
Case Studies
in Self-Determination***

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Methodology

The purpose of this compilation of qualitative case studies is to understand a select group of cases fully and in all their complexity. "The qualitative case researcher tries to preserve the *multiple realities*, the different and even contradictory views of what is happening" (Stake, 1995, p. 12). We did not engage in hypothesis testing or attempts at generalization. Instead, the nature of the method here is to be descriptive and as much as possible enable the reader to see the experience as the participants do. This information is experientially, not operationally, defined. Validity is given to all opinions and interpretations. It is for this reason that qualitative methods are so frequently and effectively used to gain insight into the experiences of disenfranchised populations.

In an attempt to define the scope of the case study assessment, according to Yin (1989), it was essential from the outset to define the units of analysis. We defined both individual participants in self-determination and the organizations that interface with those individuals as our units of analysis. We therefore have what is known in research circles as a multiple case design with embedded units of analysis.

The basic questions we attempted to answer are these:

What is the impact of self-determination on participants? and
How is self-determination implemented, given the individual aspects of the purposeful sample?

Selection

A purposeful sample of five cases were selected that would optimize understanding of the self-determination initiative. We started by choosing states according to criteria that could provide the most variety and opportunities for learning.

Hawaii

We chose Hawaii because of the cultural mix of the population and revelations that might provide about how diverse ethnic groups interpret self-determination.

Ohio

Ohio seemed particularly strong as a local control state, where County Boards have a great deal of autonomy. We expected this might present us with issues about leadership, both at the local and state levels, and the extent to which the interdependence of leadership plays into the initiative.

Michigan

Michigan appeared to be a state that was pushing the envelope both in terms of their use of waiver dollars and the intermingling of self-determination principles with managed care. We hoped to learn more about the interaction of these policy undertakings.

Maryland

Maryland was a shoe-in considering the scope of the project. The State simultaneously received a self-determination grant and a sizable waiting list initiative that would virtually eliminate the State's waiting list in five years. We wanted to explore the extent to which the two initiatives - self-determination and the waiting list - synergistically impacted the State, and whether they would influence systems change of major proportions.

Minnesota

Finally, Minnesota tapped into existing community resources to create a new service option. They used a community bank to create a user-friendly fiscal intermediary. Short of a cash grant, this component of the self-determination initiative stretched the interpretation of service financing to a new level.

In order to accumulate enough individual data for the case studies within these five states, we felt it was important to choose individuals who started their involvement early in the course of the three-year project. We narrowed our field of individuals using a snowball sampling technique (see Bogan & Biklen, 1998), and then chose the convenience sample (Stake, 1995) in each of the states. When considering individuals, we were also sensitive to other research being conducted in the states. We made a point of choosing people who were not actively involved in other research projects to avoid the undue burden of having multiple researchers asking similar questions or scheduling time with the person.

We ended the first year of our assessment having initiated two individual case studies in Hawaii, Maryland and Ohio, respectively, and one case each in Michigan and Minnesota. It is likely that we will include additional cases in both Michigan and Minnesota in the second year.

Limitations

All information provides context for understanding, but not all data are relevant. A qualitative researcher must separate data that is critical and from data that is less than substantive. "In a qualitative research project, issues emerge, grow and die. In quantitative research, as an issue becomes more refined or important, a parallel or subsequent study is started; the present one keeps its issues intact" (Stake, 1995, p. 21).

Our data are incomplete. We have not yet separated the field from the pictures, the blind alleys from the highways. At present, the cases are not fully defined, and the themes are still evolving. With time and a little more technology, Year Two of this project will likely be an essential one. We expect very soon to begin using software that will increase our efficiency in conducting qualitative analysis and improve our ability to both collaborate among multiple researchers and triangulate the embedded units of analysis.

Michigan

Local Culture

People who live and work in Washtenaw County, Michigan describe it as a center for diversity, and likewise, for tolerance of minority groups, including ethnicity, religion, sexual orientation, and differing abilities. There is a history of active political involvement in social causes dating back to the sixties and seventies. Now politically active baby boomers are pushing an agenda of tolerance established previously.

Managed Care

Washtenaw County is also a place that attempts to look at innovation. In this case, they are tackling the implementation of a government administered managed care organization. The County is attempting to blend managed care and self-determination, providing a framework of self-determination principles and accountability to the long-term care service system. While many people perceive there are risks in consolidating with other organizations, they maintain a belief in fiscal efficiencies resulting from increased individual control and creativity. The new partnerships appear to have created a team approach to quality. Because of their close interdependence, administration and providers now find themselves working on the same team. The structural change requires them together to have an uncompromising commitment to customer satisfaction and a collaborative focus on continual organizational improvement.

Individual Budgets

People perceive that one of the major differences between the long term care/self-determination model of managed care and the more established model applied to primary health care is in the decentralization of risk, from the organization to the individual. The decentralization is most obvious in the establishment of individual budgets. In the first stage of composing the individual budgets, projections were based on a combination of person-centered plans and historical information. Calculations for services were based on an average and uniform cost estimate by service type. This first stage of the process introduced the notion of portability. This first attempt at calculating individual block grants - moving from organizational budgets to individual ones - resulted in savings in the computation of staff hours. Somehow, the reshuffling

of staff time effected closer approximations and consequently identified excesses. Recently, the County introduced individual accountability. Providers are now accountable to individuals as far as reporting their budget savings and overages.

Over time, the County expects that increased efficiency will serve the unmet needs of others in the service system. They have also established a risk pool by converting 100% State and local dollars to matched federal dollars through the Medicaid Waiver. The newly created risk pool will be available to address the unexpected changes in needs of people in the service system.

Fiscal Intermediary

About half of the 22 people who have individual budgets have chosen a fiscal intermediary, which is an existing service provider that charges a fee for unbundling the individual budgets. Individuals can choose their level of control in the management of resources. The other half of the people with individual budgets have chosen to maintain their residential provider to manage their finances.

Leadership

People at all levels of the system discussed leadership as a necessary element in the success of self-determination. One could rightly conclude there are leaders at every level in the Washtenaw system with qualities that enable change while empowering people to go beyond the limits of their job roles. Qualities such as a tolerance for mistakes encourage people to take risks; working to build competence encourages autonomy; and being accessible promotes team building and an atmosphere of trust. There are visionaries throughout the system as well, enhanced in part by the Howell Group, mixed stakeholders led by the advocacy community. The Howell group meets regularly, allowing people to process and come together on ideas, while creating a direction for the system.

Remarks

on Leadership:

Donna gets the credit for that... our boss. She has created what we call a Tool Kit. And the Tool Kit has in it everything I wanted to know but was afraid to ask about budgets ... blank budget sheets ...all the information ... the costing data ... plus we are attempting to put the entire client budget and the blank format on the computer.

From the top down, there's a real County commitment to strong value-based administration, which may be unusual in County government.

[Our County Director] is willing to take some risks and she also gives us as administrators a lot of authority. She doesn't micromanage us...She really gives us a lot of autonomy and puts a lot of trust in the staff and encourages us to work towards doing that in every level of the organization.

At least a couple of meetings every month we just sat down very informally with rough drafts [of individual budgets] and questions. We told case managers it's ok to make mistakes; that it doesn't have to be a perfect draft. We learned through our mistakes to make a good budget.

on the Fiscal Intermediary:

We file all the paperwork on the person's behalf that is necessary to be an employer. We met with their employees and we have an agreement with them that say, you understand that you are an employee of Jane Doe... If you have employer/employee disputes you go to your employer, not us. The only thing that we 're doing is cutting a paycheck on the employer's behalf. At this point we 're a payroll service, basically. They sign that agreement... We issue each participant a monthly financial statement showing where their money has gone... We also provide that to [County Administration] and their case manager so that their case manager is aware of whether they 're staying within their budget limits.

on managed care:

Part of our plan is to be a strong enough system that we can compete against all new comers... What we understand is that you may not be able to bid just on a County basis; you may have to be prepared to bid on a regional basis.

Well, it's really interesting because what we 're really trying to do is to show that the more responsive the system is to individual needs, actually the viable the system will be in the long

term. And [we are committed to] person center planning and believing that the best way to manage the care is to truly turn over more and more control to the individuals and their families (as opposed to traditional managed care where they want to pull the reins in and have somebody whose never met the people authorize everything and review everything and that whole approach). So there's a real strong commitment to believing that if we operationalize the values, that will actually lead to more sustainable organization and more consumers will choose as opposed to the more traditional managed care approach.

...on fear:

...there's been some fear on the part of some families who are very used to a very traditional system and like it and think it's represents security.

on educating politicians:

A lot of our directors have done a real good job of educating the Commissioners. We have some real good support from County Administration.

on the culture of Washtenaw County:

This County is very different from the rest of the Detroit metropolitan area... Washtenaw County is a very diverse community - racially, ethically, sexual orientation - it has evolved over the years... But I can remember when I was in college, these people were weird down here. They were just totally bizarre. They were protesting the war long before anybody else was involved in it... There are so many resources here. It has drawn people from all over the world as well as all over the United States. If you were to go into a restaurant in downtown Ann Arbor, the whole world is represented.

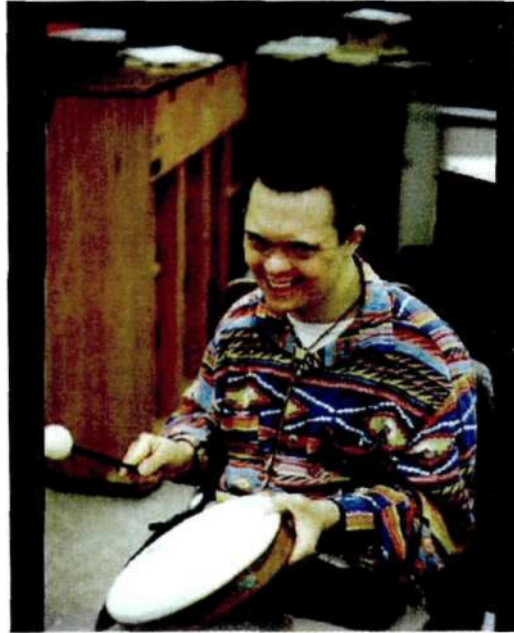
on self-determination:

The best triumph in this is that people are being given choices and I'm seeing that they're able to make choices. Whether it's the individual themselves or their family members, at least they 're getting a voice.

It's been a process, not an event. It's an on-going process. I guess lately it's really accelerated with the budget process ...now we are at a point where even the clients who don't have anybody to advocate for them are being heard. In terms of, their interests are being looked into in more detail.

on community organizing:

The thing we have yet to begin is the kind of community organizing that will begin to educate the community; that if you really, really wish to have these people become an intricate part of the community, then you must give something in return. We haven't begun doing that at all. This is all new. We haven't gotten there yet.



"Practically speaking, it's been pretty easy because I know Michael...it just comes naturally... the part that's hard is knowing that you just can't drive off on the spur of the moment for a weekend vacation."

—Michele - Mike's sister and service provider.

CASE STUDIES—MICHIGAN: Michael's Story

Michael, a 28-year-old man with Down's Syndrome, has had what his twin sister and service provider Michele has termed "a 180-degree turnaround" in his personal motivation, level of choice, and freedom to pursue his own interests. Because of the way the Michigan individual budgets have been crafted, and because of the length of time they have been implemented, participants in the self-determination initiative are beginning to have dramatic results when given the choice to hire family members or close friends (surrogate kin) to provide services. Themes that emerge when talking with Michael, his family members, and other service providers include leadership (both from Michael and others), kin relationships (as seen by Michael's blood kin, surrogate kin, and service providers), and the gaining of an independent voice, both from Michael's perspective and the perspective of those involved with him.

Emerging Issues

One salient feature of the Michigan self-determination initiative is the ability of participants to choose and pay for their own service providers, which can be family or close friends. Michael had been suffering from neglect in poorly-chosen apartment-living situations. This was not due to acts of overt malice. Rather, it was a mixture of oversight coupled with some confusion over "recipient rights". Paid service providers would not assist Michael in bathing or with other personal needs if he simply stated that he "didn't want to"—which could continue for weeks. Lichee, who is now Michael's paid service provider, describes the situation this way:

He sat around his apartment all day, every day, doing absolutely nothing... they never took him out to get his hair cut...he was refusing everything. And because of recipient rights they couldn't force Michael to do anything. But at the same time he was wearing completely filthy clothing, layering his clothing, wearing clothing that was urine-soaked, sleeping in urine-soaked sheets...his face and body were covered with acne and his hair was growing all over the place. He was wearing ripped-up clothing and all of his old clothing, like concert t-shirts, none of his nice clothing. I was embarrassed to take him out in public. It was disgusting.

In this living situation, Michael felt bad about himself and had little emotional energy for work or other activities. When Michael and Lichee heard about self-determination, they took

the initiative to discuss the possibility of having Lichee become Michael's full-time service provider. Creative support-service personnel and work supervisors joined in to craft a service package for Michael that put him in the driver's seat. It was Michael's entree' to self-determination.

Michael's twin sister, Lichee, is a petite, vivacious woman who is completing a PhD in psychology. Since becoming Michael's full-time service provider ten months ago, she has noticed a complete change in his demeanor and motivation. He now enjoys going to work, is beginning to date, and loves going out with Lichee and Scott, Michele's husband. Although Scott is not a blood relative, he and Michael have forged a very strong surrogate-kin bond. In fact, Scott often becomes involved in service provision for Michael.

Both Lichee and Scott admit that the strong kinship bond that they share with Michael makes the "recipient rights" issue less thorny. "I can make him floss his teeth because I'm his sister," Lichee laughs. However, both quietly agree that they feel it would be harder for someone without blood relatives to engage in Self-determination. Scott questions, "When does 'recipient rights' become neglect?"

Michael is a fun-loving man with a terrific sense of humor and a passion for dancing and music. Although he speaks in very short sentences, he manages to convey how much better his life is now. "I'm happy," he reports. "I like work."

In terms of his social life, he would like to be even more active. "I'm going on a date with Laurie" [a friend he asked to a Valentine's dance.] "I like dancing." He also takes music lessons. He loves going to concerts and to a nightclub called The Edge, where Lichee describes his dancing as "full-on, Madonna-style". Michael laughs and agrees. The small things, such as deciding what kind of clothing he wants to buy (colorful, ethnic-print shirts and tie-dyes) and what he wants to watch on TV (Buffy the Vampire Slayer) are as important to him as the big issues, such as how many hours he can handle at work and developing his relationship with Laurie. The important thing to Michael, and to Lichee, is that the self-determination process has allowed his voice to be heard in all areas.

Maryland

Waiting List Initiative

Having to serve 2000 people from the waiting list in the first year of the self-determination initiative is challenging to say the least, according to many from the State of Maryland. "In the middle of systems change we were asking people to do more and to do it faster, better, differently than they had ever done it." The scope of the waiting list initiative in total includes \$18 million over a five-year period to serve 5000 people. On the one hand the synergy of the waiting list and the self-determination initiatives together jump start the change process; while on the other hand, the sheer scope of the waiting list work can potentially usurp the exploratory nature of the self-determination pilot.

Resource Agencies

At the heart of the self-determination initiative in Maryland is the Resource Agencies, local authorities conceived as quasi-managed care organizations, with Boards of Directors composed on 51% people with disabilities and their families. Their purpose is to allocate resources, employ Service Coordinators and re-engineer their roles, set up and manage a risk pool of funds, and downsize the State's Regional Offices. The Resource Agencies are to be piloted in two Regions of the State, covering four Counties. The long term State plan is to operate 10 Resource Agencies covering 25 Counties. As of the beginning of calendar year 1999, the pilot Resource Agencies had not begun, due in large part to several obstacles the State encountered in start up. However, the plan is for the two pilot Agencies to be operational during the first half of 1999.

Heretofore, the State operated service administration out of the its Regional Offices. In taking apart the Regional Offices, Maryland is "doing change from the top down and the bottom up." Current Regional staff, all government employees, will have an opportunity to apply to the Resource Agency in their area for employment, but there are no guarantees for continuation of their jobs. The lean Regional Offices of the future will serve more of a monitoring and technical assistance function.

Systems Changes

Thus far, some changes that have impacted the State include these:

Introduction of non-negotiable core concepts

The core concepts associated with self-determination have been introduced as non-negotiables. There is an expectation of change at all levels of the system that stresses an individual focus, flexibility, removal of barriers, and protection of health and safety.

Opportunities for groups to process the change together

The State has facilitated and empowered a host of advisory committees composed of mixed stakeholder groups to process change together, advise on the direction of the change, and address the issue of barriers. Some feel, however, that there are still challenges in pooling a critical mass of stakeholders on the same page.

Flat rate for services

The State has a Payment System that offers a flat rate to providers of services based on 25 levels of need (determined by administering a functional assessment to every person using services). The standard rates translate as capitation fees. This enables easy development of individual budgets. However, providers have not had to compete for contracts in Maryland for some time. There are considerable changes expected of providers in Maryland given the anticipated fiscal changes and increased competition resulting from the introduction of the Resource Agencies.

Attitudes

People described attitudinal barriers at many levels of the system; from families who fear abandonment in the loss of traditional services, to paid workers who have trouble "moving from clienthood to customer service".

Licensing

The Department of Health & Mental Hygiene, Office of Licensing & Certification Administration, licenses providers in the developmental disabilities system in Maryland. The State is in the process of re-defining the licensing standards, moving from a prescriptive to an outcome-oriented approach. This will afford a great deal more flexibility to people involved in self-determination, focusing on levels of choice and satisfaction that people have about their services.

Role Changes

Service Coordinators are doing more fiscal management and linking with natural resources. Families are taking on more responsibilities, doing service coordinating. State Regional Offices are downsizing and remaining staff will do more monitoring & technical assistance. Providers will answer to people and not the State; they must do business differently and eventually be ready to act as fiscal intermediaries.

Leadership

People described Maryland as a State with overall strong leadership in all major components of the system - from the State Division Director to the Self-Determination Coordinator, to Advocacy organization directors, to family members - pushing the same thing at the same time. Some of the qualities used to describe the leaders were:

- clear values and vision
- approachable, listens and absorbs
- courageous and not afraid to take risks
- politically savvy
- compassionate and vulnerable
- empowers & facilitates others to act on their own or as a team

Remarks

on the Waiting List Initiative

...So if we hadn't gotten this waiting list money... we 'd be sort of moving things along and creating our little pilot Resource Agencies. But we had both things happen simultaneously. To pull back and kind of see the big picture and do this in a pragmatic way is pretty challenging.

The entire priorities for the waiting list initiative were built to help the self-determination initiative move into the State. So everything we 're doing with this initiative we are doing it to advance self-determination.

...on fear:

...Parents are terrified of what we are doing... They are afraid that their kid is going to end up out there in the community all alone and just abandoned...providers see this in some cases as a threat to their business.

on licensing changes:

... We've moved from very prescriptive, very restrictive regulations to regulations that are so free flowing and open that they are not going to know how to survey. So I understand that a lot of time has been devoted...to writing interpretive guidelines for the regulations.

...It's harder to look at outcome based regulations than it is to look at the prescriptive regulations that we used to have. It's easier to measure the water temperature ...than to figure out from a person who may be nonverbal that they really are happy with what they are getting and it really is making a difference in their life.

...on leadership:

We have never had such a strong group of leadership in the DD Council, in the Arc of Maryland, in the provider community, in DDA, who are all pushing for the same thing at the same time to make something happen. That's just incredible. And I think the key piece there is Diane [the DD Director] ...I think what Diane brings to this is the vision and I think that's a really key piece. She is not a micro-manager. She pulls the Division up there and lets people do what they need to do to make it happen. But she sets a clear direction... And she's not afraid to make hard decisions ...She is not afraid to take risks...And she is willing to do that because it's the right thing to do and she's committed to that.

...on fiscal intermediaries:

[Our fiscal intermediary structure] is probably going to be the agency-with-choice model that [Sue] Flanagan talks about. Basically that's a provider agency that offers fiscal intermediary services ...and that's a big part of self-determination and we 're not where I would like for us to be, not just structurally but I think conceptually.

on Resource Agencies:

The best way that we thought of to guard against cost efficiencies standing in the way of self-determination and self-choice is to put consumers and families in charge of the managed care organization. That's one of the very core concepts.

...on Rate Setting:

So what [rate setting] has done is cut down the level of negotiation with the providers. There's one set rate; if you want to be in business this is what it is and this is how we 're going to pay everybody...it gives consumers that much more flexibility in the system.



Of his home, David says, *"This is my place. I bought it! I needed it to be on one floor and to have a place for my trains. And it does."*

CASE STUDIES-MARYLAND: David's Story

David, who is in his late 30's, strikes one as an extremely self-determined person. He knows himself and knows what he wants out of life. He lives in his own trailer in a trailer park that is like any other beautiful, residential neighborhood.

Dave had specific requirements for a home, e.g.: room to keep his train collection; everything on one floor; and a Jacuzzi. (The latter was more of a hope and a dream.) His wonderful realtor, Karen, worked with him to make all of his wishes a reality. Yet the process of buying his home was not an easy one for Dave. Because he was one of the first people funded through Maryland self-determination moneys, he ran into some unanticipated obstacles that needed to be dealt with. Dave, Audra (his Service Coordinator), Nancy (Dave's mother) and Karen (the realtor) used incredible creativity to help it all come together. For example, when there was a last minute change in the amount of the down payment, they approached a number of people in the service system and in the community to come up with the balance. A provider agency loaned Dave the money, with the proviso that he would pay it back to them by working it off. Audra says that, as a result of the process of finding a down payment, David now has many more connections in the community.

Dave is employed in a work crew that cleans offices during late afternoon and evening hours. His mother does not like the idea of a work crew. But Dave insists that he loves his job. The hours are of great importance to him. He told me, "I don't work during the day! I only like to work in the evening."

A housemate from the Maryland Waiting List has recently moved in, and Dave is in the process of getting to know him. Dave says, "(My housemate).. is like a new shoe. I've got to break him in."

Emerging Issues

David's success is due, in large part, to effective self advocacy. Audra says that, when she first met him, Dave had learned to say, "Everything is fine," even though he did not have any of the things he wanted in life. It took some encouragement to bring him out. Yet, by the time I met him, what David wanted was very clear. He was not afraid to say what mattered to him, and

he was not about to stop until he got it. He was not in any way obnoxious about what he wanted; he just had a clear vision of what should be in his life and a determination to get it. Thus, for David, his strong, clear sense of SELF really directed the self-determination process. In the second year, we will look more at the question of how a strong sense of self can contribute to the success of the self-determination process.

David also had the strong support of Audra and Nancy. As leaders in the process, David, Audra and Nancy all displayed certain characteristics that were essential to Dave's success. These include: creativity, vision, determination, and a strong sense of the wider issues. In the second year, we will continue to look at how these leadership qualities affect the success of the self-determination process for a particular individual.

At the time that I visited David, his housemate from the Waiting List had just moved in. David faced TWO challenges with relation to this change in his life: negotiating what form this new relationship would take; and negotiating with the provider about how this change would affect their role with him. (Specifically, he needed to avoid having his home turned into "the Ridgeway house". Already, one person at the provider agency talked about having David and his housemate share one staff person and referred to Dave and his housemate as "the guys at Ridgeway.") It seemed that Dave's self determined life might become coopted; yet there were people in David's life who would step in to prevent this from happening. In the second year of the study, following up on how things work themselves through may shed light on several wider issues: how do we avoid having old pieces of "the system" knock someone's self determined lifestyle off track?; and, when someone's "personal leaders" meet up with this type of obstacle, how do they deal with it?

CASE STUDIES-MARYLAND: Joshua's Story

Joshua, who is 17, lives with Joseph, a housemate who also receives services, in a home that Josh owns. The house belonged to Josh's parents; but they decided to modify it and sell it to him as the central piece in Josh's plan for supports. Josh's parents developed the skeleton of the initial plan themselves, and then called upon a provider and Maryland Service Coordination to help them fill in some details and put it into action. Prior to this, Joshua had spent time in an institution and then in a children's group home. Both were terrible experiences for Josh, and for his family. Now, Joshua lives in his own home in a lovely neighborhood of which he is very much a part. Josh attends his local High School. Ricky, Josh's full time Aide at school, also lives in the house with Josh and his housemate. The school system pays Ricky's salary at school, and he receives a supplement from MRDD for providing back-up care in the home. He and Josh are very close. Other staff were hand-chosen by Josh's mother, Jackie, and approved by Josh. All have great affection for Josh and are committed to giving him their best.

Emerging Issues

Family involvement has been central to Josh's success. Josh's family designed his supports. And, with his mother, Jackie, as his Case Manager, the family continues to be in charge of the process. As changes occur, Jackie is at the helm, keeping supports centered around Josh's needs and talents. What does this mean with regard to how self-determination works for people who DON'T have well informed and highly involved family members?

As the lead advocate in Josh's life, Jackie displays certain qualities that keep supports working well. These include: the creativity to get around obstacles; a clear sense of who and what will fit into a happy life for Joshua and of how to put the pieces together; a positive outlook; and a thorough understanding of the wider issues, afforded Jackie by her involvement as a parent advocate. What part does having a "leader" (this could be the person him/herself) who has these characteristics play in ensuring that a person meets with success in utilizing self-determination?



"I thanked RWJ and selfdetermination for giving back our lives. Because we lost our lives for those years that Josh was in an institution or a group home. We were just dictated to."

--Jackie - Josh's mother

Minnesota

Local Culture

One is readily struck by the innovations that are seemingly embraced in both the State of Minnesota, and in the case study site, Dakota County. Sweeping changes that are often met with resistance in other locales are welcomed here. Change and innovation are hallmarks of the local culture, according to the people with whom we talked. People at all levels pride the service system for being user-friendly, though another common refrain is that "this is the hardest thing I have ever done professionally." People seize the notion that paid workers have a responsibility to people with disabilities. Part of that responsibility is to work to make the system understandable, even if it means adding to their workload.

Fiscal Intermediary

At the heart of the self-determination initiative in Dakota County is the Fiscal Intermediary, piloted for the self-determination project. The Fiscal Intermediary is a local, County-based community bank. The bank provides multiple individual checking accounts, owned by Dakota County, and held jointly by the County and respective service recipients. The County advances payment into the individuals' checking accounts according to the person's planned estimates for service. The account is later reimbursed with Medicaid dollars as service is delivered. It provides a seamless, single stream of funding to the consumer that is community based. Those who work within the system have an explanation for the success of this creative and innovative structure, "we have wonderful financial people. They don't ask if, they ask how."

Individual budgets are based on a predetermined, historical amount. Each person is provided with that figure before they start the individual planning process. Saving money is not a goal of self-determination; however, individual control over the process is. Financial support of the individual budgets is managed in a way that overcomes regulatory barriers inherent in any one categorical funding stream.

Other System Changes

Managed Care

The State is home to a pilot managed care grant from the Robert Wood Johnson Foundation in the Counties of Olmstead and Blue Earth, also participants in the self-determination pilot. As such, there are many simultaneous and synergistic innovations to service delivery being explored.

Waiver Amendments

The State was able to successfully get approval from the Health Care Financing Administration (HCFA) for amendments to their Title XIX Home and Community Based Services Waiver. The amendments modify funding and service limits, allow coverage for an expanded array of services (particularly "consumer-directed community support"), and allow local county authorities the ability to utilize cost savings generated by service efficiencies.

Management Information System

Software developed by the State enables local administrators to track individual budgets, including each budget's categorical funding mix, and simulate the fiscal implications of people moving to differently priced service options.

Consumer Report Guide

A local advocacy organization is publishing a "consumer report guide" that enables consumers to shop for services offered by service providers.

Leadership

The leadership at various points in the system is described as very effective, though different in what it offers. Leaders at all levels noted the necessity to provide a user friendly service system, with "whatever it takes". One of the most visible qualities of the leadership has to do with risk taking. The risk is embedded in *nonmaleficence*, or "do no harm." The belief expressed by several local leaders is that "the system really exists for us" and at times causes harm to people with disabilities - "The side effect of a lot of our services are a total loss of family, community, or any kind of feeling of power."

State leadership is perceived as effective at the systems level, providing technical assistance, advocating for broad political and regulatory change, and bringing diverse groups together to promote and support the change process. Local leadership provides team building through education, a consistent set of principles, and barrier removal.

Remarks

on shifting power & realizing the implications of the current system:

I honestly believe if you go through this process, if you are really changing, you will get mad, you will get depressed... The side effect of a lot of our services is a total loss of family, our community, or any kind of feelings of power that the individual has. It seems like a little more than side effect. But nonetheless, most people come into the field wanting to do good. And as they examine really the side effects of the system taking everything over, not just health and safety but people's lives, it isn't very good. And so it becomes quite depressing when you realize that.

We would pay great money to split families up but no money to keep them together. So I can pay for, if you want to go on vacation and you want to leave your person with disabilities behind but if you want to take your person with disabilities, I can't help you pay for that. ..So even though in a society that says ... yes, we believe in community, yes we believe in family, we do our damndest to kill it.

...on shifting roles:

And so the basic notion of social work is as much as possible to be in a helping relationship. And I think we're far from that in our field. We 're in to it giving and care taking and controlling relationships. We 're not much in to helping relationships.

...on the proverbial critical mass:

Scientists went on an island and they took fruit and they took sand. And the monkeys wanted the fruit but they couldn't eat it with the sand on it. And what they found of course, not surprising to you or most of us I guess, is that a couple of female monkeys figured it out first - that if you went down and washed the fruit in the water then they could eat it. And at first, only a few other monkeys picked up on it but when they hit a certain number ... and they called it the 100th monkey, then all of a sudden everybody did it. Not only did every monkey on that island do it but even on an island that was adjacent did it. Now, they could never quite figure out how that happened. But I really believe in that. I believe that in Minnesota we 're getting very, very close to critical mass, that this is the way we'll be going behaviorally. But what will be backing it up attitudinally and how it will actually play out, boy that will be all over the place.

...on role changes:

The role shifts are so incredible and are needed and they 're not just needed by the system, they are needed by the people receiving the services.

Traditionally, the locus of control to providers is that the social worker runs the show. And with this [self-determination] the locus of control returns to the parent. A provider, if we 're using traditional services, a provider can call me and ask questions and raise issues and I'll say, well, those are good but you need to talk to the person paying the bill.

on natural supports and conflict of interest:

But our system is truly not set up to facilitate or support the natural psychological emotional security development of our folks. It isn't. It takes away the power of most people who can know somebody well enough to have a relationship. And every time they try and do that we say there's a conflict of interest. Well, all I have to say is, as a system we should be able to monitor conflict of interest. The conflict of interest is not nearly as big a problem as destroying somebody's natural support system. So let's knock it off and focus on not our liability but what we 're really trying to accomplish.

on the staffing shortage:

To use all our waiver money that we get, we have to encumber at over 130% of what we 're actually going to spend because they can't get staff out there. In-home services are averaging about 55% [turnover] across the state.

What's happening is that many, many people aren't getting the support that they were authorized for because there just aren't the staff to do it. Or there's so many staff [because of high turnover]. I had one mom telling me about, I can't remember how many hours of PCA type service that they had coming in to their house. It was every morning and every afternoon of every day and there were sometimes five different people in their house during the week. It was a revolving door. And they are saying ... this is just way too much stress on our family in our house all the time.

on purchasing services:

The way that things seem to have been set up in the past is that everything is an all or nothing proposition ... either use the provider all the time or you don't use them at all. And what I'm seeing is many, many combinations of provider based support and relationship based support and informal network support. And that's what most people are doing, combinations of that.

... With some of the families that I work with right now, their services and their providers aren't actually all that different than what we had contracted for under the traditional services. What a couple of the families have done is they've left their formal vendors behind but actually hired outright the employees from the vendors. So they still have the same service people working in their homes but now they are a direct hire of the family instead of being a direct hire of a vendor that the county contracts with.

on getting a life and not a service:

And so the first question that we usually ask people is what do you think you need? Not what the service team wants but what do you think you need? Try to get it out of a service discussion. It's hard to do that sometimes but people usually know what they need if you can get them to have the conversation about life not about services and then try to put support around it. So we've been doing some of that for a very long time and so this is like a step in our evolution.

...on equity:

Taking a look at it, I think the other big thing is if you have big disparities between people who are on the Robert Wood Johnson self-determination [project] and people who are continuing to use contracted providers through the county system. I mean, self-determination people start being able to buy services cheaper, more effectively, maybe don't need as much, and the budget is reduced. And then you have people who have chosen not to be in self-determination, who continue getting \$5,000 or \$10,000 more ... people who are taking the challenge of, okay, if that's apart of the expectations of the program, if I chose to participate, I may get fewer dollars because I'm effectively managing my funds.



"Self-determination in motion"

CASE STUDIES-MINNESOTA: Sheryl's Story

Sheryl is a tall thin woman of 36 years who lives in a house with one roommate. She immediately draws you into her home with a smile, an extension of her hand and a hug. It is clear that she is happy about having visitors. Her use of some sign language, manual and verbal gestures, and a few spoken words, draws the outsider into the beginning of a relationship with Sheryl.

Sheryl lives in a suburb of Minneapolis with one roommate in a small rambler in one of the older neighborhoods of this suburb. Her house is staffed 24 hours (no live in staff) and is owned by a local agency providing residential supports to people with disabilities. Sheryl receives one to one support at home. Her current living situation is the result of her desire to live in a home after spending a large portion of her life in Intermediate Care Facilities (ICF). Her request was listened to and acted upon by her guardian of 6 years, Glen.

The story goes back a little. When Sheryl was three years old her parents decided that they could no longer care for her, and they have had little involvement in her adult life. In 1989, Sheryl met Glen. Glen worked in Sheryl's then residential program doing overnights. A year later he began working at Sheryl's employment agency and was assigned to work one to one with Sheryl for two years taking her to her job sites at Pizza Hut and at a pet store. As Glen describes, "She's got a great personality. I think that what endeared me was I worked with her for two years, one to one then got a new job. She always has adjustment problems with new people and this [the new person] one didn't work out so the social worker decided to move her [Sheryl] to...a behavioral day program. It's around that time I started thinking, this isn't right; so I sought guardianship."

It was their personal relationship and the time spent together that has created such a strong connection between Sheryl and Glen. In 1990 during a personal futures planning meeting, as Glen recalls, Sheryl said she wanted to live in her own house. In early 1997, after pursuing it for a number of years, Sheryl received a waiver and she moved to her current house. In mid-1997 Glen heard of Robert Wood Johnson (RWJ) funding and immediately called. Because Sheryl was currently going to move into a semi-independent living situation (SILS) and had a waiver, she was able to participate in RWJ. In many ways, her participation was due to timing. Things were in place at the time the funding became available.

The first year was difficult for Sheryl. There were numerous transitions and staff turnover, which caused her a lot of stress. Now staff has stabilized and Sheryl is very happy where she lives and likes the people who currently support her. During the day, Sheryl spends time at an agency specifically designated for people with challenging behaviors. Trying to find a new job for Sheryl is one of Glen's current goals.

Sheryl's budget includes both her residential and day program expenses and transportation. Dakota County, Sheryl's county of residence, deposits her funds into her checking account and Glen pays the bills directly. It is up to Glen and Sheryl to decide how they want to spend the money.

One thing that Glen has done is to purchase a car in Sheryl's name for \$1,200. The intention was that staff could drive her to and from work and around the community. In doing so, he has been able to eliminate high transportation costs and payment for overhead. Currently, Glen is looking at one to one support for Sheryl to be able to work in a more meaningful job. Glen says, "She is currently not happy in her day placement, as work is limited. It's a behavioral program and she is more capable. It's hard to sit here and have people tell me...no that won't work. I've done this; what do you mean it won't work?"

Emerging issues

A major issue that has come up is that, when Glen comes up with new and creative ideas, he meets with obstacles trying to enact them. For example, in addition to the challenges he faces with the car (getting insurance and staff not being willing to drive it), his current pursuit of new employment for Sheryl has brought new difficulties. He has obtained figures from different agencies to provide one to one support for Sheryl in a work setting. While the figures vary greatly, his main concern is that much of the cost includes unnecessary services. Glen provides some insight: " I think that providers are very stuck in their ways; this is the way we do business and who are you to come in here and tell me how to do my job?" Individuals often naturally use more common sense; and, when given their own budgets, they try to use the money in the most economical way possible. Obstacles are presented when the service system hasn't caught up to the ideas of the individual, family, or guardian. Flexibility is a critical issue.

Another issue for Glen relates to the security that is built into the existing service system. If a person purchases services on an individual or on an as needed basis, the safeguards that would exist within the service system are often not in place. For example, if someone gets sick, they naturally have back up. Glen's concern is that if he didn't have an agency providing services, the onus would fall on the family or guardian to pick up the pieces, which is often difficult.

Self-determination has brought about interesting and complex questions, for individuals, families, and service providers. Each new idea raises critical issues that challenge existing services and families. The solutions will most likely emerge from the process. They will take time and willingness from all involved.

Ohio

Leadership & Organizational Culture

Delaware County, Ohio is known widely for its innovations in many areas of the service delivery system. A variety of people described it as a "rebel County", saying it has been that way since 1988 when the current Director started. Predominant themes in the Director's leadership style are risk taking, responsibility, and conflict resolution. He uses all three to encourage new ways of thinking throughout the organization. He "facilitates rather than dictates", enabling paid staff to operate in a culture where taking responsible action and learning from mistakes are the *modus operandi*

In addition to the Director, other leaders were identified in Delaware County. Though the identity of individual leaders varied according to the respondent and the role they occupied, many of the same qualities of leadership were consistent throughout:

- Maintains a clear vision and direction
- Embraces conflict & diversity
- Learns from conflict & mistakes
- Encourages others to take responsibility
- Asks forgiveness instead of permission
- Focuses on process
- Politically savvy
- Vulnerable
- Maintains an expectation of change
- Promotes individual choice

There is a strong sense of a predominant culture in Delaware County - an open, flexible, trusting one with a team-based approach to problem solving and the freedom to be creative. One gets a strong sense that many of the principles in self-determination are actualized throughout the local system. People appear to be "on the same page" because in their work they experience many of the same principles they are asked to practice.

Role Changes

Changing roles are the result of a system re-organization that preceded self-determination. Though self-determination has had some impact on changing roles, similar principles have played a part in the service system in Delaware County for a long time. In fact, several people described the Robert Wood Johnson grant as providing the necessary leverage to take the next step, to explore changes in the rules and regulations that act as barriers. Nonetheless, paid County staff have labored hard to make self-determination a reality for people with developmental disabilities in Delaware County. And most say their job is harder now than before, given the need to work differently and learn new things. Some of the County jobs that have changed are as follows:

- Resource Allocators [a.k.a., "alligators"] - These former mid managers are now acting as in-house fiscal intermediaries, individual advocates, and contract managers.
- Service Coordinators - These positions are volunteers chosen by the individual with disabilities to assist them in planning and facilitating their service plans and in developing a network of natural supporters and friends. Many of the Service Coordinators that have been chosen are already employed in other capacities in the system.
- Case Managers - The role of case manager has narrowed from carrying out traditional case management to now doing intakes, and helping the person establish necessary developmental disability services: "getting the team up under the person."

There appear to be some role conflicts with the changes, in that some staff are exploring the limits of their role boundaries in relation to potential risks people with intellectual disabilities may face. The tension between individual autonomy and professional beneficence is one that has come up again and again not only in this initiative but in relation to the overarching paradigm change taking place in our society. It is an ethical dilemma faced by professionals in many health related disciplines today (see Beauchamp & Childress, 1989; Schwartz & Ogilvy, 1979).

Remarks

on responsibility:

Self-determination, just as with any right, has a responsibility. And I'm still waiting for the responsibility to kick in...it's a learning process, a developmental process.

...on risk:

...don't be afraid to go out on a limb because that is where the fruit is.

on taking risks and accepting failure:

We don't have the white knight syndrome.

...on Delaware County, Ohio:

This has always been a rebel County.

on blurred role boundaries:

Somehow you lose yourself in that process, too. And that part is probably kind of a down side.

on changing roles:

It's like everybody fell off of this mountain. And at the bottom was this thing called self-determination but we still had people hanging onto branches on the way down. And some of them are fighting the money issue and they can't get by it so they are staying there. And they are stuck bad on that limb and they are not coming down to where everybody else is.

So it was years and years of struggling to get heard. And now it seems to me like we've reversed roles. And the clients are clear. They know what they need. Now we're the ones who have to bust our ass to get stuff done. And it's not that way with all of them but a lot of them it is.

I don't think I know the answers anymore. And in my old job I knew the answers. And I think that's a hard, hard thing for people to grapple with, the ability to kind of ride the wave and know

that you are making sound decisions as you go. But there's not really a path so you are kind of making it as you go. And I think that's been probably the hardest thing for people actually involved.

on self-determination:

It's not really self-determination that he's doing but it's the individualized stuff and I try not to look at just the self-determination project but individualizing supports for people and anybody can have those kinds of things. So that's probably why you hear people say ... I'm not involved in the grant... but they are involved in the concept and the individualizing of support.

...on social control:

we seem to not be able to give up the idea of controlling people. We either control them with programs, social engineering or we 're controlling them by trying to say, here's a set of values, family values that everybody has to live by. Instead of saying, the people have within them the values they need, we just need to help support them.

...on the role of community:

Partnerships in self-actualization basically sharing common values and I think that's what society is ... is people coming together and saying I feel this way ... or ... this is a value ... this is important to me ... I chose to identify and associate with others who value the same thing and who reinforce that. When you have people telling you who you are and what you are, is not valued and therefore, you need to change to fit their view of you ... that's where you get the external control.

I think organizationally, our institutions ... church, government, or whatever ... tends to take the view that man is basically evil and needs to be trained and structured and ruled and controlled in a way that causes them to behave for the common good... and to overcome the "self ... I think that's ... I think all of this is a balance ... our structures cause us to do that and I think the struggle is to bring a balance that in fact, man is basically good and what we need to focus on is allowing them to realize and develop their own potential and not what we necessarily see for them.

...on Maslow's self actualization:

What we 're talking about here is Maslow's self-actualization. Self-determination is self-actualization. Basic needs have to be met first and this is my whole point. If you have a willy-nilly system that has money being spent, particularly with influence of others, on self-actualization activities (taking a vacation), and you 're not addressing basic health and safety

needs, and the next month the individual is evicted from their home because somehow the system has permitted or fostered or encouraged the individual to become self-actualized and they don't have food, who is managing that money? First of all, a fiscal intermediary is wrong for allowing the individual's basic needs not to be met. And secondly, I doubt that the individuals on the whole, make those bad decision, but they're led to those bad decisions by professionals who are just egging them on - you deserve a vacation, we 're going to see that you get to Florida, sorry, the money ran out with our grant.



"Tom's team and Tom working together has been great. That's really how he manages to stay on his own, in his own apartment."

CASE STUDIES-OHIO: Tom's Story

Tom lives in his own apartment, and reports that he is proud of his lifestyle. He has arranged his life around his choices; but his freedom has been hard won. A year and a half ago, soon after Tom became funded through self-determination, he found himself in a life-threatening situation. His diabetes had ranged way out of control; and his doctor insisted that he move to a nursing home. Tom and his team put together a plan to keep him out; but Tom had to propose some severe self limitations to make it work. Because Tom cannot control his eating, he asked that no food be kept in his home. Rather, his support staff would bring over food one day at a time and supervises his eating. And this is what has happened. Tom looks at his diet plan, and chooses what he will eat each week. From there on in, his meals are highly regulated. During the time since his crisis, Tom has lost 80 pounds. He looks great and is thrilled about the weight loss. Yet members of his team worry about the restrictiveness of his plan.

Indeed, the team that Tom has chosen concerns itself with EVERY aspect of his life, and is the key to his success. His aunt says, "Tom's team and Tom working together has been great. That's really how he manages to stay on his own."

With relation to work, when Tom became funded through Ohio self-determination, the first thing he told people was that he no longer wanted to work in a workshop. People paid immediate attention to his request to get out; yet his work choices were somewhat limited by the existing system of supports, so that he ended up working in a laundry enclave in a local hotel. He says that he likes his job very much.

There is currently a new possible threat to Tom's ability to choose, in the form of a change in Tom's funding. His support has just been switched over from local moneys that come through the County Board (which is how the DD system works in Ohio) to a new Ohio Medicare Waiver through the Ohio Department of Health and Human Services. While the Waiver will have a very positive affect on Tom financially, it could also cause him to lose the support staff whom he knows and likes. The problem stems from the fact that the agency that currently provides Tom's residential supports is not yet Medicare certified. During the eight months that it will take for their application to be processed, Tom could be forced to hire "...a stranger off the street". This is particularly unfortunate because Tom has said that choosing staff and having

continuity in his supporters is one of the most important aspects of his new life. Tom's team is very much aware of this problem and is working hard to avoid a loss of choice.

Emerging Issues

The strong advocacy of Tom's team has been the key to his success, despite the obstacles he has faced. As a team, they exhibit certain characteristics, e.g.: creativity; an ability to take the long view; and a thorough knowledge of the wider issues. Is it imperative that someone's "personal leaders" display such characteristics in order for self-determination to work for him/her, despite ongoing challenges?

The leaders at the County level interface with Tom and with his team. In fact, Sharon, his Contract Coordinator, is both a County leader and a member of the team. Certain aspects of the leadership at the County level have affected Tom's success in a positive way. Some issues which this raises are: What characteristics of leadership on a macro level affect how self-determination will work for an individual? How do these qualities compare to those displayed by a successful individual's "personal leaders"? How do these two sets of leadership qualities intertwine?

The effects of the new Waiver on Tom's system of supports will be important to look at in the second year of the study. In Ohio, everything in the MRDD system is tunneled through the local County Boards. Thus, there is no state bureaucracy for people to deal with. Yet bureaucratic issues managed to creep into Tom's plan when his financially beneficial change in funding was promoted; he will now have to deal with an arm of the state bureaucracy that is outside the DD system altogether and is uninformed about self-determination. Where circumstances are so complex (as they often are), how can we avoid having bureaucratic considerations get in the way of someone's ability to remain truly self-determined?

Hawaii

Implementation Factors

Several things are clear about self-determination in Hawaii. First, most stakeholders welcome it, and second, it is a place like no other where self-determination principles have the potential to flourish. The initiative has moved slowly, however, due to several factors.

Leadership

There appears to be a crisis in leadership at the moment relative to the implementation of self-determination. One of the two key leaders of the initiative (from the Department of Health) is no longer positioned to influence the project, and the other (from the Developmental Disabilities Planning Council) has been less formally positioned. As such, the implementation effort was stalled and currently is adjusting to the change.

Structure

The original plan, to create a managed service organization (MSO - the local authority), has been impeded by a lack of system structure to support it. In fact, the Department of Human Services (the branch of State government that deals with Medicaid) has ceased work on obtaining a waiver from the Health Care Financing Administration. The waiver would have allowed the MSO to both funnel money locally, and utilize cost savings generated by service efficiencies.

Although the MSO has a contract with the State, it is not fulfilling its originally intended role. It has established a local presence on the two pilot sites but there seems to be confusion between the roles of case managers and the MSO's staff. Further hampering the effort, the MSO is a service provider that intended to relinquish its service provision when the MSO became functional. But since the MSO is not fully operational, the organization has continued to provide services. This places it in conflict with other service providers in the state. Finally, there are key stakeholders in the system that believe the MSO is an unnecessary structural change, and that self-determination can be implemented without it.

Perspectives

- Families - Though only two families are involved in self-determination, both from one pilot site, they expressed concern, frustration, and fear about the continuation of the project. Both are satisfied with what they have been able to accomplish and fear that the future of the project is in jeopardy.
- Service Providers - The service providers in the two pilot sites feel caught by the conflict between the self-determination principles and outdated regulations that require them to provide service in traditional ways. They are also wary of potential problems that could arise as a result of the MSO's perceived conflict of interest.
- MSO - The local authority feels alienated from the rest of the provider community and lacks administrative support and sanction to function as the MSO.
- Case Managers - There is general support for the principles of self-determination at all levels of the case management system. But at the local level there is concern about the lack of utilization by people in the service system - a perceived lack of trust and confidence in the new initiative.

Systems Changes

- Act 198 Amendment - An amendment to Act 189 was passed last year that legislated the individual planning process, individual control of dollars to effectuate the plan, and self-determination for people with developmental disabilities.
- Waiver amendment - the HCBS waiver was amended to eliminate individual capitation rates (though strict guidelines were subsequently defined) and expand the definition of services.

- Training - A broad effort was made to bring about awareness and guided facilitation/training around the principles of self-determination in the past year. The effort appears to have reached many of the stakeholders.
- Managed Service Organization - A contract was signed with an MSO, and local representatives were hired for each of the two islands that constitute the pilot sites of the self-determination project

State Attributes and Local Control

Hawaii ranks 50th total spending for developmental disabilities services in this country (Braddock et al, 1998, p.49). The State does not have an abundance of resources to support people with developmental disabilities. But an even more obvious challenge to people is the geographic separation of the Hawaiian Islands, accessible to each other primarily by airplane. Each of the five major islands has separate ethnic communities, separate cultures, and communication challenges with the central funding and regulatory government offices in Oahu.

The State is composed of five major (and almost equally represented) ethnic groups - Caucasians, Japanese, Hawaiians, Portuguese, and Chinese. There is a history, dating back to colonialism, missionaries, and plantations, that speaks to cultural preservation, oppression, and trust. In each case, outsiders came to the islands and attempted to change the people through dominance. Many of the people we interviewed casually mentioned the influence of these historical events, as if deeply engrained in the cultural history of the islands.

Finally, the native Hawaiians (a combination of both pure and mixed Hawaiians) represent approximately 20% of the population of Hawaii. Yet, they are disproportionately represented as the highest ethnic group on both the active recipient list and the waiting list for developmental disabilities services (personal correspondence, 3/99). They are also disproportionately represented in many other disabling, long term and chronic conditions such as diabetes related glucose intolerance - nearly double the overall US rate (Hughes, 1998), and cancer mortality - the second highest (Tsark, 1998). In short, "Native Hawaiians have some of the poorest health status indicators in the nation" (Miike, 1987). This finding led to the Native Hawaiian Health Care Improvement Act of 1988 (and reauthorized in 1992). Concurrently, the

Native Hawaiians developed an infrastructure in response to the Act called the Papa Ola Lokahi that enables four local authorities to administer and advocate for health care services for Native Hawaiians.

The structures will provide a mechanism through which Native Hawaiians can interpret and address their needs on their own terms. Results of a 1998 Summit on Native Hawaiian issues call for Native Hawaiians to explore culturally sensitive ways to improve education and health care (particularly in understanding the Medicaid system and looking for other alternatives, p. 38).

As two groups who have been disenfranchised and are trying to find a voice, the Native Hawaiian and disabilities movements are clearly aligned. The extent to which the two are related and might find common ground upon which to advance their respective efforts is worthy of exploration.

Remarks

on adapting in culturally sensitive ways:

We had an interesting training program dealing with high risk pregnant women...we had three groups - Filipino, Hawaiian, Japanese. They delivered the same message and it was delivered in three different ways. With the Japanese clientele we had to deliver it privately between them, the social worker, the nurse, and the pregnant woman. For the Filipino community it had to be done in a group -4 to 5 women together. For the Hawaiian community it had to be a group within the Hawaiian community... Hawaiians have a strong family group but their definition is different than yours or mine... it is a large group; it could be a whole community.. they rely heavily on that area and that community. They will not go out and seek help.

...on family involvement

...I haven't seen families being involved, asking for more money... They are not there pushing us - to give them this freedom, give them this choice to allow them to spend money. That has to be done.

...on advocacy:

... Our parents want for their kids but they don't think their kids can do it for themselves.

...on self-determination as offering freedom:

...to understand the Native Hawaiian world view is a complex and extensive process which requires an open mind and acknowledgement that most things unique to the Native Hawaiian world view are inadequately expressed through Western theoretical constructs. The near decimation of the Hawaiian language has subjected the expression and interpretation of Hawaiian beliefs, practices and values to a foreign language and Western world view filter which is often intolerant of differing perspectives. (Tsark, Blaisdell & Aluli, 1998)

...on the State contracting for the Managed Service Organization:

"...it really seems like they just wanted to find someone to do it [operate the MSO] for them and they didn't think through it, they hadn't even asked the question ... how is the money going to get to this MSO? They hadn't even asked that. But yet they were putting the bid out there, they

didn't even have any idea of the logistics of it, how to get the money to the MSO, what the MSO's authority or abilities would actually be."

on regulations in Hawaii:

"Our waiver is really restrictive and there are a lot of state regulations that are imposed. And one of the regulations is, in order to work [direct service] with people with disabilities, you have to first take this Part A test which agencies administer. And it's like 20 questions or something and you have to pass it with 75% and then you have to work hands-on with people with disabilities. And then after 90 days, you have to take the Part B test, which is administered by the Department of Health and it's like 100 questions and you have to pass with 80% or something. And you have two times to pass it and if you don't pass it within two times then you're pretty much blackballed from the system or something. And we have a lot of people with English as their second language [have problems]... And the Department of Health provides [the test] and charges \$40.00 a person to take it....And then they are the ones that administer the test.

on provider support for the MSO:

"There's a bill before the legislature right now to develop an MSO or an area agency system as a means of doing business in our state. And I'm the only provider that ever testified for it. All of the providers testified against it. They all say there's not enough facts ..."

on case management support for self-determination:

"But yet the case managers won't promote [self determination] and they won't talk about it.. "

on self-determination:

I haven't met anybody who didn't support the philosophy of self-determination. But I've met a lot of people who have no intentions of changing to make it happen.

...on leadership in Hawaii:

We've lost all of our leadership. Bill Christoffel really supported this [self determination] and it sent a really loud message when he didn't get appointed... with Bill, this was a passion

...on supporting State jobs:

We have 165 employees working at Waimano training school and hospital and 14 people live there. The State spends 7 million dollars a year. It's such a waste, it's all about jobs. Because if you have this large pool of state employees you have a lot of voters.

on being a responsible bureaucrat:

I think we have an obligation to the public, not to save ourselves but to serve the public. That's what it comes down to; that's how I've always operated; I have no desire at all to protect State jobs.

on person centered planning:

And so then the [worker] was invited to go to this meeting and she thought it was just a general meeting. Well, as they 're in the meeting the case manager is writing notes and the coordinator asks, when are we going to do the person center plan? Not because she didn't think she 'd be invited, she didn't even know the person. And [the case manager said], oh, we 're doing it right now. And no one even knew it was going on. And there were people there that were invited that didn't even know the family.

on the continuation of the MSO:

The problem is that that [the MSO] was somebody's idea. And our staff [Department of Human Services], because we 're responsible for fiscal payment, met with the Department of Health staff, item for item, and were wallowing in all the details about how do you make this little entity have the same accountability that we do to HCFA, how do they have the data, how can they collect the information, how can they make the payments? At which point, the DOH decided, stop, stop, this isn't worthwhile; we 're not going to do this. So we put it all in writing because I thought, this is going to come back to haunt us... because we know that [some people are] still saying go forward. But the Department of Health has said, cease and desist ... so we said, okay, we've ceased.

...on implementing self-determination:

...It appears that the Department of Health in this grant, has identified, has taken the philosophy of self-determination to now make it something operational. But we can't feel it and touch it and that's where our confusion is. We don't see where it differs from what's happening now so we 'd like to see instruments; that has been difficult. I think that's where the confusion is...

*"I think for the first time I could really start dreaming.
The D.D. population is giving us a chance to re-evaluate
ourselves...to grow.. to be better people.. this is their gift to
us...I believe that."*

Shea and Honey

CASE STUDIES-HAWAII: Shea's Story

Shea is an 18-year-old man who lives with his mother Honey and his sister in a rural area on the Big Island of Hawaii. His mother describes him as a very social and loving child who enjoys swimming and being included in things even though he doesn't directly participate. Getting to know Shea has been difficult until recently because of his numerous seizures and heavy medication. According to Honey, "We don't know who he is or what he likes!" Shea has been seizure free for the past six months. His mother believes that this is a result of a special diet that Shea has been on over the past few years as well as a decrease in his medications. Shea is beginning to enjoy his surroundings and the people around him.

Honey is a strong advocate for her son, and in many ways had been thinking creatively about how best to provide support for Shea before becoming involved in self-determination. In the fall of 1998, as part of the self-determination initiative, Honey began to work with Easter Seals, the designated Managed Support Organization (MSO) in the State of Hawaii. Honey worked out a budget with their representative. The biggest difference that she sees is that she has more freedom to, as she said, "...act as the employer in acquiring the services that Shea needs. I have freedom to embrace it now ...not to be secretive. I don't have to pretend that I don't know!" She has been able to raise the salary she pays her support people and has hired two people now with whom both she and Shea feel comfortable. Using her budget, she has been able to increase what she pays her staff, as she is eliminating some of the cost she had with having to hire nurses. She believes that if the people she hires feel valued and connected to her family they may stay with them longer thus deterring the constant turnover they have experienced. Honey has always believed in the need for Shea's support staff to understand him and connect with her family. She feels this is especially true now as they move toward more community involvement, "He needs a network, a circle of people." In the emerging connections that Shea is having with his family and with people around him, his mother sees great potential especially if they are allotted flexibility.

Emerging issues

In the short time Shea has been involved in self-determination, Honey has been very satisfied. She has been able to re-negotiate payment and to hire two support people whom she can pay a little more, thus creating a more valued atmosphere and without having to pay overhead costs of an agency. Though there remain many details that she still struggles with in relation to things like who can administer medications (trained nurse or personal assistants), she creatively problem solves around these issues. Of more immediate concern is whether or not what they have developed will continue when the MSO contract ends in June. Honey says, "It's scary, I've got my people in place. Will I have to change in June?"

This sense of uncertainty is the reason that she also believes there is an over-all lack of involvement and trust among families and there are only two families involved in self-determination. "Many parents have given up; they lack trust. When you have people making decisions without input from those it's affecting.. you get limited involvement." Things have developed slowly in Hawaii, according to Honey, but they are continuing to develop. Further communication and embracing the potential grassroots leaders that exist within families will be an essential component for the future of self-determination in Hawaii.



"All of this is an attempt to see where the potential may lie, and always in the past, everybody said there wasn't any potential."

--Curtis SR. - Charlie's father

CASE STUDIES-HAWAII: Charlie's Story

At age 42, Charlie is beginning to feel comfortable in his home, in his surroundings and in his life. Charlie recently moved into his own home which was built for him by his parents, Curtis and Thelma. He currently shares his home and is supported by Mike, who has formed a strong and supportive relationship with Charlie. They have lived together for about a year. Charlie lived a good portion of his life on the mainland in a variety of states and agencies. His parents brought him back to Hawaii when they returned there to retire. His mother was born on the Big Island, as was Charlie.

Charlie has an extensive vocabulary when he chooses to use it. Until recently, much of his communication has been through his behavior; but he is beginning to socialize and talk more in his home when Mike has friends over. He is also making his own choices more frequently. For example, according to his parents, he is saying he doesn't want to spend all Sunday afternoon with them as he has done in the past. Smiling, because they see this as growth in their son, Curtis explains, "We've really let go to where we occasionally drop over there during the week for a little bit. But none of those all day Sundays anymore."

Through the RWJ initiative, Curt and Thelma were prompted to create an arrangement for Charlie that gives him a one on one caregiver. In his plan, it was also determined that Charlie needs 24-hour care. Curt and Thelma were able to maintain and subsidize this level of support while waiting for the MSO to be put into place. It wasn't until the end of December 1998 that they knew for sure that Charlie would get the necessary funds to continue the needed support. Charlie spends his days at the local provider; the time he spends there has just been extended. In addition to the individualized care, the Curt and Thelma were able to give Mike a raise, which was a very valued and important part of making this successful. They are also able to purchase some respite services and have built a room onto Charlie's house for that person to stay. Even with this plan, Charlie's parents still subsidize some of the costs for Charlie to live in his own home.

With these individualized supports in place, and a decrease in medication (Charlie has been on psychotropic drugs for a long time and has been weaned off for the past two years), everyone has seen positive changes in Charlie. He now sits with people and carries on a conversation and even engages people in public when out in a restaurant. These changes have

brought stability to Charlie's life, something that has not been in place for quite some time. With this stability, he and his support circle are able to pursue things that will add to the quality of his life, like making friends and becoming involved in things he enjoys such as basketball and swimming. His father smiles and says, "What I'm anxious to think about and try to plan for is how do we take advantage now of these new social behaviors and help him feel better about himself as a person. To get him into something more meaningful."

As Mike sees it, "Charlie is growing let's allow him to grow as a human being." Curtis enthusiastically followed with, "it's been so good [self-determination], I'm optimistic, it can't fail!"

Emerging issues

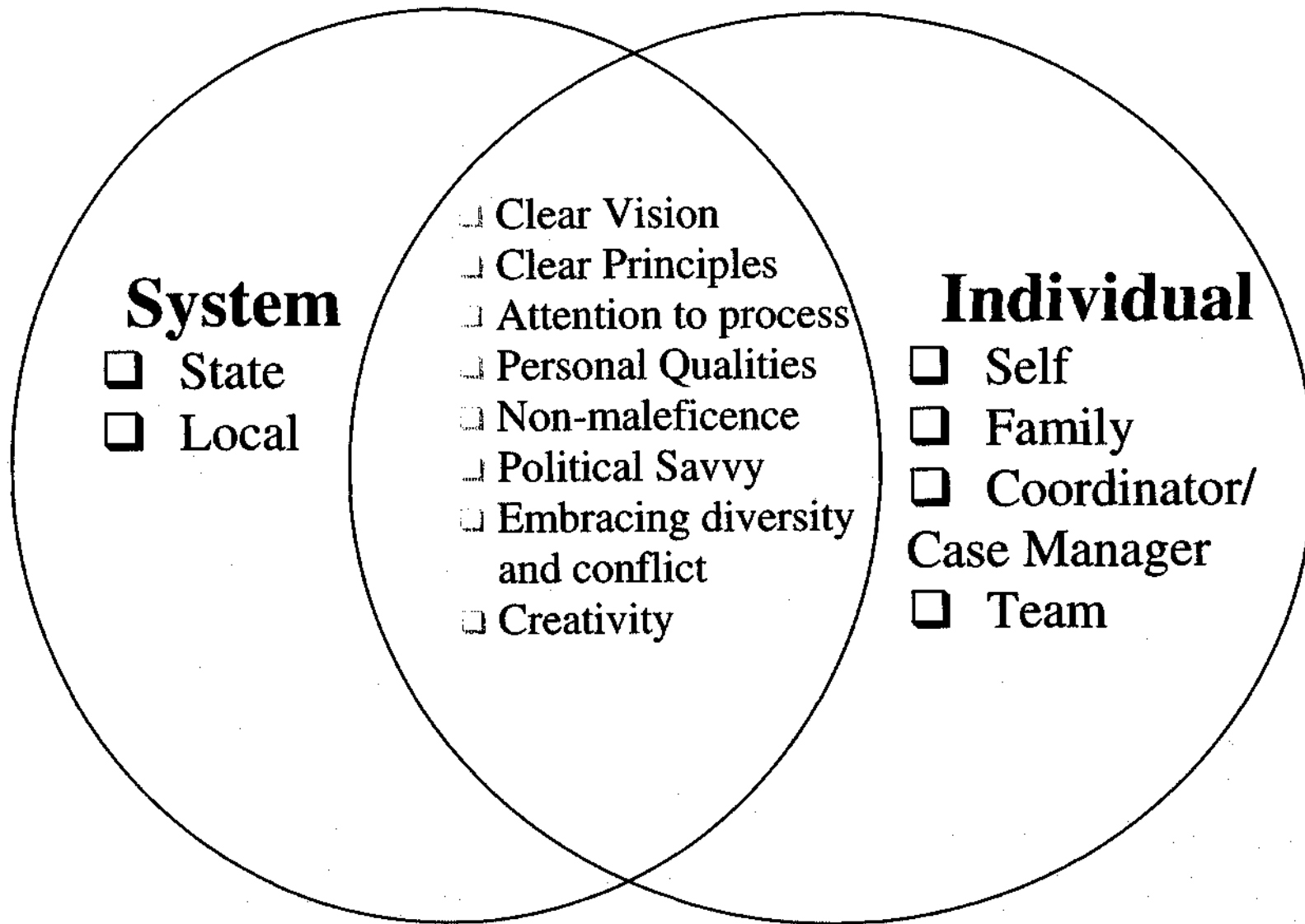
While the changes in Charlie's life are positive and related to self-determination, the major and most imminent concern to the family relates to whether the MSO's (Easter Seals) contract and consequently self-determination will continue after June. Curtis states, "We've got to have some insurance [that it will continue] soon." He also wonders about the flexibility, and "...whether the system will change and be flexible enough to serve the needs of people. The skepticism that exists broadly among families was an issue raised on numerous occasions. This lack of broader involvement also raises the issue of broader cultural representation in Hawaii. Curtis believes this is directly connected to the distrust families have of the system. Curtis explains, "Families are skeptical because other promises have been broken."

Trust is a critical factor as it relates to issues of cultural diversity. The strength of family ties, be it within the native Hawaiian ohana (family), or the Japanese and Filipino cultures, is critical. Often decisions are made for the benefit of the family versus the individual. "Family is so strong," explains Curtis, "if you really get a chance to get down there to the grassroots, people are going to tell you... we really do want the best for our child.. they're just not sure how to go about it." Local control and recognition of cultural values that impact family involvement as well as the interpretation of self-determination by cultural groups raise critical issues to explore, especially in Hawaii with its great diversity.

EMERGING

THEMES

Leadership



LEADERSHIP

The quality of state and/or local leadership can have an enormous affect on how self-determination will progress in a given area. Where leaders have certain key characteristics, self-determination will move forward apace. Where these characteristics are lacking at the top, it becomes much more difficult to work through the complexities of instituting change throughout the system.

Individual leaders/advocates can affect progress made by an individual with self-determination in much that same way that systems-wide leaders can affect progress overall. These leaders/advocates may include the person him/herself, a family member, a Service Coordinator, or the team as a whole. If certain leadership characteristics are displayed by whomever is promoting a person's interests, self-determination will be more likely to work well for that person. And it is also more likely that the person will continue to be self determined despite challenges posed by health, bureaucracy, old ways of thinking, etc.

A few of the characteristics which have been noted in effective state and local leaders, as well as in effective personal leaders, are: clear principles and values; clear direction and vision; creatively negotiating obstacles; ability to absorb what others are saying; approachable; unafraid to take risks; politically savvy; compassionate and vulnerable; encouraging others to take responsibility; embracing diversity and conflict; focusing on process; and a do first and apologize later attitude. In the case of the personal advocates, "creatively negotiating obstacles" should go at the top of the list, since the manner in which people and/or their advocates contend with difficulties imposed from the outside can ensure their continued success with self-determination.

Emerging Leadership Issues

1. What does it mean that there are two sets of leaders- on the macro and micro levels- that make self-determination work? Why do these people exhibit many of the same characteristics?

2. Is there a need for willing partnership between the leaders at these different levels, since if they work cooperatively they can find ways together to get things done? If so, how does this work in practice?

3. People at all levels are called upon to understand the roles of the others. How do effective leaders- on the macro and on the micro levels- reach such an understanding? How do they express that understanding?

4. How do effective leaders on each level handle obstacles to self-determination? In particular, how do they handle obstacles imposed by pieces of the existing service system that are resisting change? How do macro and micro leaders/advocates bring about change in lagging areas of the system so that people are no longer impeded in their ability to set up and maintain a self determined lifestyle?

KIN RELATIONSHIPS

According to Stack (1974), kin relationships are one mechanism whereby oppressed people can pool scarce resources in order to survive. In addition to blood kin, Stack identified "fictive kin" relationships—relationships in which people with no blood tie to an individual were given familial titles (e.g., "aunt") and accorded the same treatment as blood family members. We found similar relationships to be valuable to people who are pursuing self-determination, although we feel the term "surrogate kin" more clearly captures the relationships in this case.

For people pursuing self-determination, blood kin and surrogate kin may be thought of as opposite ends of a continuum, where the relationships may change or fluctuate over time. For example, in Michael's case (Michigan) a surrogate kinship relationship developed between himself and Scott, his sister's boyfriend. When Lichee and Scott got married, the relationship moved closer to a blood tie in the continuum. In other cases, kin may remain in surrogate status as close friendships develop between people stemming from a variety of sources.

Extended family members may become important in an individual's kin network. In fact, participants in our research in Hawaii made reference to the concept of *ohana*, the extended family comprised of an individual's entire support network, both blood kin and surrogate kin. Surrogate kin relationships may become very important for an individual with few or no ties to blood relatives.

When persons who are pursuing self-determination have the option of hiring a kin member (blood or surrogate) as a service provider, it allows the pooling of individual resources to occur in a very synergistic way. Rather than getting a second job or making other sacrifices in order to ensure service provision, kin members are placed in a supportive position for which they are uniquely qualified.

Through this fiscal control, individuals are able to take charge of important decisions that affect their lives and increase their level of personal freedom. Moreover, our case studies strongly indicate that people who have moved from having strangers or people who were not well known to them as paid service providers to having kin members as paid service providers are much happier with the latter. In sum, the integration of kin relationships as a key part of the self-determination process shows great promise.

SOCIAL MOVEMENTS

"The right to self-determination includes the right of self definition"

Sharon Venne-Cree Nation

Social movements are one of the most effective forms of political action and cultural change in society. They promote structural change in order to create a more equitable society, and have targeted underlying causes of social problems such as discrimination, poverty, and issues of equity among disenfranchised groups. They often have effects that go beyond their specified goals. Organized around the concept of collective behavior, social movements have been seen as a form of collective challenge to some aspects of the norm or status quo. They have organized around specific issues and have involved mass movements based on specific conditions or injustices perceived by particular groups.

In the United States such movements have been common from the beginning of the century but are commonly seen today as gaining significance with the civil rights movement in the 1950's and 1960's. This gave way to numerous other movements such as the women's rights movement, farmer's worker movement, gay and lesbian rights movement, and the disability rights movement.

Often social movements arise from a long history of institutionalized discrimination and what some refer to as cultural abuse. In her article, *Cultural Abuse*, Margaret Noyes describes Native Hawaiians and some characteristics of a widespread abuse that impacts them in the following ways:

- feelings are ignored
- people are ridiculed or insulted as a group
- values and beliefs are insulted
- approval/affection is withheld from you as punishment
- person/group is called names
- person/group is humiliated
- your abuser refuses to socialize with you

- you are kept from being able to work
- your abuser controls your money
- your abuser makes decisions for you
- you are manipulated.

These are common experiences of people with disabilities.

When one begins to understand self-determination as a social movement, where a domineering group of people take control over the lives of others, one can then begin to draw links and connections to other movements of struggling for autonomy. Self-determination as a means to begin to achieve some equity (power), within the existing system is an emerging theme within this research on self-determination. It also appears to be a critical part of the broader self-advocacy movement and the to advancement of the rights of people with disabilities.

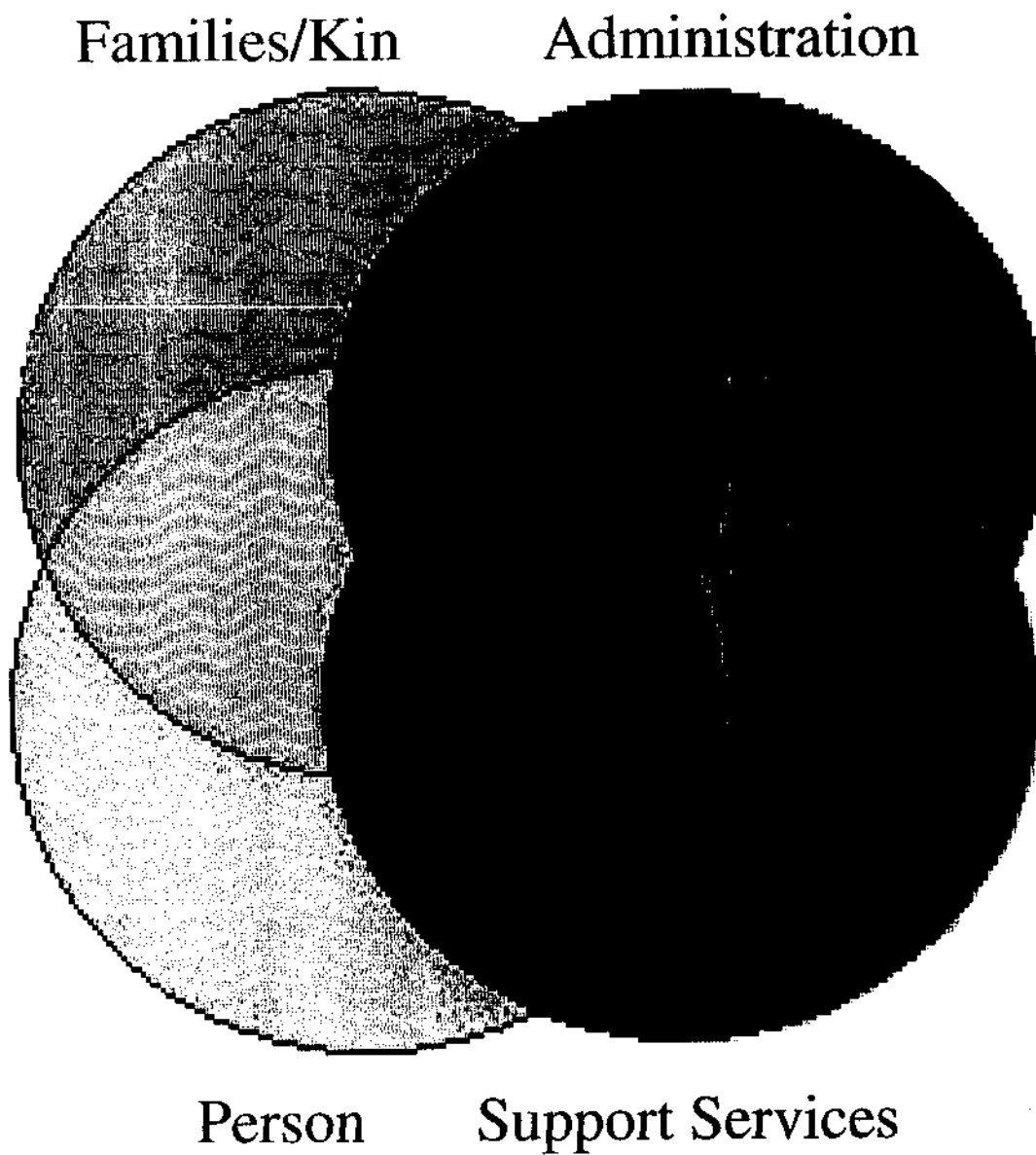
Understanding self-determination from this perspective also provides the opportunity for people within it to learn, and connect with current other existing social movements working toward similar goals of equity. One clear example of this is in the State of Hawaii. For the past 10 years the self-determination movement for Native Hawaiians has been gaining popularity. Many of the issues that Native Hawaiians face in their movement toward self-determination share common threads with the self-determination movement for people with disabilities. Research has shown that social movements are not self-contained and that these links spill over to affect others. Clearly people involved in self-determination have recognized these connections.

"It's happened with...they call it the feminist movement...it's happened with Blacks...it's happened with everything. I mean, I'll call it anything they want, if they want to go by self-determination. But I've always known it has to do with human life...bottom line."

Parent, Hawaii

"If you read the Declaration of Independence, it applies to Charlie... All men (women) are created equal...and they are not treated that way. It's a criminal act of the worst kind."

Parent, Hawaii



Shared Values



Differences-
Roles



SHARED VALUES, DIFFERENT ROLES

The major stakeholder groups involved in self-determination share agreement on the core definition of the concept - freedom, authority, support and responsibility. In most cases, it appears there is an intensive period of time at the outset of the project, where people process and interpret its values and meaning in their lives/jobs. Through that process, there is both formal training and group discussions. This is where the rhetoric begins the gradual shift toward implementation.

Each of the major stakeholder groups - the person with disabilities, their families, administrators, and support service workers - have played a different yet critical role to play in making self-determination a reality.

1. Person - People with disabilities for the first time in the history of the service system have a key place at the table. They are gaining a voice, and in doing so are coalescing with others, including friends and neighbors (a.k.a., natural supports), other self advocates, and other social movements. These associations in part serve to create identity both in the community and in the broader milieu of social causes.
2. Families - The families of people with developmental disabilities appear to be moving from a secondary support role to a vital one involving service coordination. In many cases family members are acting as the primary advocate for the individual and the support network.
3. Support Service Workers - people who directly support others with developmental disabilities are changing roles from care-takers to facilitators. Their relationships are deepening, and/or they are acting as a critical link for other relationships.
4. Administrators - State and local administrators have the job of changing rules and regulations. In the process of doing so, it is necessary for them to build support for the change, and to rearrange the structures that will support the change.

The roles people play are so interdependent, the initiative seems to depend on successful team work. The uncertainty of change can be unsettling. Given a clearer understanding of these roles and their relationship to each other, people can learn to embrace rather than resist the transformation. As the self-determination initiative evolves, then, the roles each group play are significant to understand.

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